

# LESSONS LEARNED IN SUPPORTING INDIVIDUALS WITH COMPLEX SUPPORT NEEDS

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In recent years, we at Kerry's Place Autism Services (KPAS) have learned to challenge ourselves about what "hard to serve" means, especially with respect to supporting an individual with Autism Spectrum Disorder (ASD). More often than not, we find that it is the situation or environment that has become challenging for the individual, leading to a response that we may define as "challenging." For example, when for whatever reason(s), support situations break down, individuals with ASD may have difficulty in coping and may exhibit (revert to) difficult behaviour. Very often, this is behaviour they had learned in response to previous environmental or social challenges. In other examples, individuals behaviour difficulties may be in response to specific health (including psychiatric), sensory or social challenges that they are now facing. Parents, agencies and professionals often identify the individual's challenging behaviour as the problem that must be addressed directly, rather than identifying and dealing with the underlying cause(s). We find that if the underlying reason(s) for the "difficult behaviour" can be identified and resolved, the "difficult behaviour" is much more easy to address, and often dissipates over time without much other action.

Each individual with ASD is unique and different (as we all are). Therefore, the rationale and path to success for each person had to be studied, understood, and tailored to his or her needs. As such, we've learned to better identify some of the circumstances that can make a situation difficult.

Some of these factors may include:

1. Reputation: A reputation has developed, and thus the person is labeled as "difficult" or "aggressive". This reputation has defined how others perceive this individual and so, may limit their opportunities.
2. Communication: Often there is a breakdown in communication between key parties (i.e., individual / family / service provider) whereby family members and support providers disagree and are in conflict about how supports and services are to be provided.
3. History: Often there is a long history that has badly wounded the person with ASD. Examples of such history include institutionalization, limited relationships, trauma, and / or abuse.
  - a) Some individuals have been victims of overt and direct discrimination and restriction of human rights, including the restriction of access to community services and inaccessibility to due process enjoyed by others in society.
  - b) Others have lived in institutionalized settings that have clashed with their sensory, environmental, and social needs.
  - c) Some individuals do not have relationships with people who can understand their history, interests, strengths and support needs with empathy.
  - d) Also, due to their increased vulnerability as a result of the nature of ASD and societal reactions to their disability, many have experienced abuse and / or other forms of trauma.

4. Transition: The individual may be in transition between support settings and not have adequate skills to bridge this transition.
5. Dual Diagnosis: Many individuals with ASD also experience mental health difficulties.
6. Families having their own special needs: Family members may have their own special needs such as mental health difficulties and / or a history of being wounded.
7. The individual and their family have been (or perceive they have been) inadequately served by the Developmental Service Sector, the Mental Health Sector, the Education Sector or a combination of these. Many families are faced with long “waiting periods” for supports and services. These services may seem by the family to be provided at the convenience of the authorities and staff of the various “services systems” rather than where and when they may be most needed. Some of these families may have supported their children (adult or otherwise) at home, at great personal cost, while they see other families, who seem to have less or no greater need, being provided with extensive supports and services.

The key point in identifying these circumstances is not to place blame, but to identify that it is often the circumstances that make the situation challenging rather than the person with ASD. Given this, it is important to consider support strategies that address the difficulties where they lie, rather than focusing only on “changing the person.”

While the specific approaches used have had to be developed to support the needs of each individual, our work has allowed us to develop some principles or approaches that have had some general applicability.

### **1. The Importance of Functional Analysis of Behaviour and Tailoring the Environment to Meet the Needs of the Individual, i.e.: “Deep Listening.”**

Aggressive or self-abusive behaviour in persons with autism almost always has communicative value that can be used to develop support strategies to assist the individual by those who are willing to listen. Sometimes the message is that the individual is in physical pain or mental distress, or wants or needs something that they do not have. It is important to analyze what function the “problematic behaviour” has for the individual, or in other words, what it is that is being communicated.

Most often, if one deals effectively with the medical problem, or creates environmental conditions so that the individual’s needs and/or wants are addressed, the problematic behaviour decreases. It can take some time for this to happen, since many challenging behaviours have often been in place for a long time and are entrenched. Further, it is often difficult to stop those people around the individual from continuing with their behaviours that may have led to and maintained (reinforced) the individual’s behaviour.

If difficulties have occurred for a length of time, the individual may have become increasingly frustrated and learned that aggression and self injurious behaviour is sometimes successful in getting them what they want. Obsessive compulsive disorder and other types of behaviour may have been adopted as ways of temporarily reducing stress or of satisfying particular sensory needs. Without truly understanding the person,

the response from support providers is often inconsistent, delayed and unrelated to the wants or needs of the person with ASD. The individual may be ignored, punished or rewarded for the same behaviour at different times by different people. The resulting confusion, fear and anxiety are felt most acutely by the individual and may pervade the support environment.

Unfortunately, in the past it was common to see the challenging behaviour itself as the problem that must be eliminated. Professional “behavioural modification techniques” have often been called on to do this using positive reinforcement, negative reinforcement, or punishment. Even if such approaches are successful in modifying the behaviour in question, problematic behaviour often reappears in another form because the real underlying issue has not been addressed.

## **2. Developing and Maintaining Trusting Working Relationships with the Individual and his or her Family/Support Circle**

Mistrust between professionals, agency staff, managers and family members may result when family members feel that the former are not responsive to what they feel are legitimate concerns about quality service issues. Such fundamental disagreements on approach can lead to mistrust, which over time, tends to magnify the impact that legitimate service issues may have as well as make resolution of them more difficult.

Disagreements may arise between parents, agencies and professionals over various approaches/treatments that have been popularized on the internet or in the press. The internet and popular literature is abound with anecdotal information regarding poorly researched or unresearched causes and cures for ASD. Many family members, not having a background in how to critically evaluate such findings, do not know how to separate the “wheat from the chaff”. They may reject soundly researched approaches and accept those which are not.

Of course, one cannot state that some of the anecdotal interventions do not work for some people or that the soundly researched ones will work for everyone; research results bearing, as they do, on the “balance of probabilities.” That is, the former has not been proven to definitively work beyond what you could expect with a placebo, while the latter has, at least within the context of accepted experimental convention.

KPAS, for example, does not object to (but will not usually pay for), interventions like naturopathic medication/nutritional supplements, or other approaches that may lack credible or sound research. These interventions are not discouraged as long as they are not likely to do harm, either in themselves or by hindering access to other necessary support including medication prescribed by a licensed health care practitioner.

Conflict and misunderstanding between and among the individual, his or her family members, professionals and service providers can often be addressed by agreements and memoranda of understanding which outline clearly and respectfully the roles and legitimate responsibilities of each of the participants. In the early stages, when minor deviations to the agreements may occur, these must be addressed quickly and cooperatively.

Clarifying roles and responsibilities in a respectful way, with the availability of appeal and conflict resolution processes, should be straightforward and applied equally to all participants. This is very important in maintaining trusting working relationships and keeping things “on track.”

As with the individuals we support, there is always a reason behind the actions of family members and our goal is to listen and understand these reasons. Also, as is often the case with those we support, the actions and behaviour of family members can often be seen as attempts to communicate through their frustration and challenges.

Understanding the reasons for this behaviour and responding accordingly can lead to more fruitful approaches, even if this means having to confront the limits of what the agency or professionals can do in relationship to what the family may want. Indeed, sometimes if there is too big a gap, the best thing to do is for both sides to agree that the individual and/or his or her support circle may be more comfortable with another service provider. Most often, however, this clarification can lead to a more trusting productive working relationship.

### **3. The Need for Collaboration Across Sectors, Agencies and Disciplines**

Resolving “hard to serve” situations often exceeds the capabilities of any one agency. Collaboration across sectors such as health, social services, education and justice can be critical, as can pooling resources, expertise and responsibility across agencies and professionals. Unfortunately, at times, responsibility for such cases has been regarded as the sole responsibility of individual agencies; professionals have not always sufficiently valued input from others; and various government sectors have tended to find ways of defining cases as outside of their mandate, should ambiguity on the subject of mandate exist.

Likewise, it is important to note here that the lessons learned in terms of best practices can be implemented by any group of people if there is a committed goal amongst the individual, his/her family, service providers and medical professionals, to assist the individual in gaining the best possible quality of life for their unique situation. These core principles of (1) Understanding the person, (2) Building on the strengths of the person, and (3) Gaining Common Understandings, can be utilized by any team committed to supporting individuals with complex needs.

Many generic developmental service agencies such as Community Living Associations have a long and solid history of supporting individuals with complex needs. What they do and how they do it can be strengthened through partnerships with specialized services such as Kerry's Place Autism Services and Medical / Psychiatric Services.

There is a limit to what specialized agencies such as KPAS can do in providing direct support to individuals. We feel that we can achieve our mission of “enhancing the quality of life of persons with ASD,” much more broadly by sharing what we have learned in supporting individuals with complex needs. We are undertaking to do this by increasing partnerships and collaboration with other agencies, professionals, and government officials. This is an endeavor that we hope will assist the community and service

providers in building their capacity to support the individuals with ASD in their home communities across Ontario.

It is positive to note that, as reflected in this case study, the sense of “shared responsibility” and collaboration across sectors, professionals and agencies seems to be improving. (The creation of the four “specialized developmental services networks across the province should also represent a major step forward in this regard.)

#### **4. The Importance of the Biopsychosocial Approach**

The Biopsychosocial Approach in which individuals, family members, and professionals share information and work collaboratively, within their mandates and areas of expertise, is extremely important in dealing with complicated situations. This is especially evident when there are concurrent mental health concerns.

In recent years, KPAS has been extremely fortunate to be able to collaborate with three prominent consulting psychiatrists who specialize in the treatment of individuals with Dual Diagnoses. Together with the direct support team, and the psychological/ behavioural and social work input from staff of our Psychological Services and Family Support Department, the consulting psychiatrists support individuals at a series of “clinic days” in three sites across Southern Ontario (Brampton, Aurora, and Thomasburg).

Since the inception of these clinics, we have observed a decline in both the intensity and the overall number of crises for several of the individuals with the most complex needs that we support. This joint approach has been successful because the collaboration of psychiatric and psychological supports delivers the most appropriate intervention at the most critical times for the individual. Appropriate medical intervention targets the existing mental health issues if they exist. Many times, the presenting features of serious mental health issues are mistaken for behavioural features associated with Autism Spectrum Disorder. Once intervention has been initiated to treat the mental illness and stability has been achieved, behavioural intervention may or may not be indicated.

#### **5. The Need to Reach “Critical Mass” in Expertise and Resources to Achieve Treatment “Breakthroughs”**

It can be costly to develop and implement an effective plan to “turn difficult situations around.” It is obvious that this plan must be based on firmly researched best practices. If the plan is not sound, or if is not implemented effectively, a great deal of money can be wasted with little or no positive benefit. In like manner, if corners are cut so that there are not sufficient resources to effectively implement the plan, the treatment can fail.

However, to get results, we have to expect results. Therefore, KPAS generally feels that it is better to begin these “higher cost interim treatment interventions” with appropriate individualized fiscal allocations, rather than annualized funding, with the expectation that costs will reduce as the intervention progresses and is successful. This being said, it is important not to get locked into a rigid schedule focusing at cost reduction, as each situation is unique and progresses at different rates.

For those who are prepared to make this investment, the returns result not only in cost savings but more importantly a greater quality of life.

### **Conclusion**

There is not much that is esoteric or complicated about what we have learned about supporting individuals with ASD and their families over the years. This learning has come from committed and continued listening to those we support and their families.

We believe that if applied more generally and consistently, many more individuals could be availed of a much better quality of life at less cost than is being experienced now (on average). This includes individuals now living in the community with their families, in “group homes”, in institutions, and in forensic units.